

General

Guideline Title

Guideline recommendations and their rationales for the treatment of neonates, infants, children, and adolescents. In: Shared decision-making in the appropriate initiation of and withdrawal from dialysis, 2nd edition.

Bibliographic Source(s)

Guideline recommendations and their rationales for the treatment of neonates, infants, children, and adolescents. In: Renal Physicians Association (RPA). Shared decision-making in the appropriate initiation of withdrawal from dialysis. 2nd ed. Rockville (MD): Renal Physicians Association (RPA); 2010 Oct. p. 93-110. [56 references]

Guideline Status

This is the current release of the guideline.

The Renal Physicians Association reaffirmed the currency of this guideline in 2015.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Recommendations

Major Recommendations

Establishing Family-Centered Shared Decision-Making

Recommendation No. 1: Develop a Patient-Physician Relationship That Promotes Family-centered Shared Decision-Making for All Pediatric Patients with Acute Kidney Injury (AKI), Chronic Kidney Disease (CKD), and (End-Stage Renal Disease) ESRD

In addition to involving pediatric patients to the extent that their decision-making capacity allows, the nephrologist should involve parents in determining health care decisions. If the parents request to involve other family members in shared decision-making, this request should be honored. If the treating nephrologist believes that a pediatric patient's parents are making decisions inconsistent with the best interest of their child, the nephrologist should involve medical ethics consultants or hospital ethics committees, mental health professionals, pediatricians specializing in child abuse and neglect, mediators, or conflict resolution specialists. These experts can assist in determining the reason for the parents' treatment choice and in determining an appropriate course of action. It is imperative that the nephrologist take steps to ensure that the pediatric patient has an adult advocate who is capable of participating in health care decision making. Court involvement to order medical interventions over parental objections should be a last resort.

Family-centered shared decision-making process is recommended for all advance care planning discussions in which treatment options are discussed and treatment decisions are made. Education geared to the cognitive abilities of the parent and pediatric patient about the medical condition, prognosis, and available treatment options is an important component of the family-centered shared decision-making process. The

pediatric patient's primary care physician, and in the case of the critically ill pediatric patient, their intensivist should be encouraged to participate in coordinating care related to treatment decisions made by the pediatric patient and his/her family. In the intensive care setting, patients with AKI will usually have multiple medical problems and the concept of shared decision-making necessitates a multidisciplinary approach including nephrologists, intensivists, and others as appropriate, and decisions about acute renal replacement therapy should be made in the context of other life-sustaining treatments.

Informing Patients and Parents

Recommendation No. 2: Fully Inform Patients with AKI, Stage 4 or Stage 5 CKD, or ESRD and Their Parents about the Diagnosis, Prognosis, and All Appropriate Treatment Options. Inform Children and Adolescents in a Developmentally Appropriate Manner, and if Feasible, Seek Their Assent about Treatment Decisions

Treatment options include: 1) initiating or continuing dialysis; 2) transplantation for ESRD; 3) not starting dialysis and continuing optimal medical management; and 4) stopping dialysis and continuing to receive palliative treatment. The nephrologist and the medical team should make every effort to inform parents about the potential benefits and burdens of dialysis initiation or dialysis withdrawal before providing or withdrawing treatment. In the rare circumstances when this is not possible, parents should be informed as soon as possible about the rationale for emergent initiation and the efforts that were made to contact the parents before changing the medical plan.

As a component of informed permission/informed assent, and in keeping with the on-going process of both shared decision making and advance care planning, the treating nephrologist may determine that dialysis is no longer providing net benefit (i.e., the risks or burdens outweigh the benefits, the underlying condition is progressive and dialysis is only prolonging the dying process without improving the quality of life during the dying process). In this case, the nephrologist and the medical team should approach the family and discuss the undue burden of dialysis given the patient's medical condition and recommend stopping dialysis and intensifying palliative treatment. This will typically occur in the intensive care setting and intensivists should coordinate the shared decision-making in the context of other aspects of supportive care. Children and adolescents should be given the opportunity to communicate their feelings and perceptions regarding the benefits and burdens of dialysis to the extent they desire to do so and their developmental abilities and health status permits. When seeking informed permission/informed assent for discontinuing dialysis, the medical team should explicitly describe comfort measures and other components of palliative treatment that will be offered.

Recommendation No. 3: Facilitate Informed Decisions about Dialysis for Pediatric Patients with AKI, CKD or ESRD; Discuss Prognosis, Potential Complications, and Quality of Life with the Patient, Parents, and/or Legal Guardian

Nephrologists should rely on population based survival data, using adjustments for confounders, to discuss prognosis, potential complications, and quality of life with patients, parents, and/or legal guardians. During these discussions, the nephrologist should acknowledge that the ability to predict survival in the individual patient is difficult and should reassure the patient and family that there will be ongoing opportunities for additional discussions regarding prognosis over time. Given the likelihood that health status changes for the better or worse are likely to occur in pediatric patients with AKI, CKD, and ESRD, discussions about survival odds and physical and psychosocial outcomes should be repeated when dramatic changes in health status occur. Each discussion regarding prognostic outcomes and patient/parent decisions regarding treatment should be documented in detail and dated. This documentation should be easily identified and accessible in the medical record. In the event of questionable understanding of the prognostic data, it is recommended that additional resources be offered to the pediatric patient and his or her family to ensure a reasonable understanding of likely outcomes and to allow for informed decision-making regarding treatment (see Recommendation No. 8).

Resolving Conflicts about What Dialysis Decisions to Make

Recommendation No. 4: Establish a Systematic Due Process Approach for Conflict Resolution if Disagreements Occur about Dialysis Decisions. Use Conflict Resolution Interventions When Family Members Disagree with One Another, When Children Disagree with Their Parents, When Families Disagree with the Health Care Team, or When the Health Care Team Disagrees about Initiating, Not Initiating, or Withdrawing Dialysis

The following types of interventions are recommended to resolve conflicts: additional medical consultation(s); involvement of pastoral care; palliative care consultation; a multidisciplinary conference including sources of support for the patient/family from within or outside the institution; short-term counseling or psychiatric consultation for the child and/or family and/or consultation with a hospital based ethics committee. When the health care team believes that non-initiation of dialysis would constitute medical neglect, consultation with available child protection specialists would be appropriate to help determine next steps. Court involvement should be used as an intervention of last resort.

Facilitating Advance Care Planning

Recommendation No. 5: Institute Family-centered Advance Care Planning for Children and Adolescents with AKI, CKD, and ESRD. The Plan Should Establish Treatment Goals Based on a Child's Medical Condition and Prognosis

Family-centered advance care planning is recommended for infants with poorly functioning or nonfunctioning kidneys due to genetic conditions and

those with a non-reversible urological or kidney abnormality. In the event that the health care team has information that the viability of a fetus with suspected multisystem organ involvement is questionable, family-centered advance care planning should occur before the birth of the baby. This will allow the health care team to be able to act decisively in light of the neonate's health status and prognosis at the time of delivery.

Advance care planning should be an ongoing process in which treatment goals are determined and revised based on observed benefits and burdens of dialysis and the values of the pediatric patient and the family. The renal care team should designate a person to be primarily responsible for ensuring that advance care planning is offered to each patient. Patients with decision-making capacity should be *strongly* encouraged to talk to their parents to ensure that they know the patient's wishes and agree to make decisions according to these wishes. Ongoing discussions that include reestablishing goals of care based on the child's response to medical treatment and optimal quality of life is the mechanism by which advance care planning occurs. Discussions should include the pros and cons of dialysis as well as potential morbidity associated with dialysis. Kidney transplantation should also be discussed if appropriate.

Children and adolescents should be allowed to participate in advance care planning commensurate with their preference and developmental status. Parent or pediatric patient questions regarding discontinuation of dialysis if the patient's medical condition becomes irreversible and non-responsive to currently available treatments should be addressed frankly. Such questions can be used as a springboard for obtaining information about parent and child wishes regarding end-of-life care. Assurance should be given that the pediatric patient's comfort is paramount in the event that dialysis is discontinued. In addition, such questions should be used as an opportunity to explicitly describe comfort measures and other components of palliative care.

Making a Decision to Not Initiate or to Discontinue Dialysis

Recommendation No. 6: Forgo Dialysis if Initiating or Continuing Dialysis is Deemed to Be Harmful, of No Benefit, or Merely Prolongs a Child's Dying Process. The Decision to Forgo Dialysis Must Be Made in Consultation with the Child's Parents. Give Children and Adolescents the Opportunity to Participate in the Decision to Forgo Dialysis to the Extent That Their Developmental Abilities and Health Status Allow

An example of a clinical situation in which forgoing dialysis is often considered is an infant with multisystem organ failure for whom dialysis would be burdensome and would serve only to prolong dying. Forgoing dialysis should also be considered for a pediatric patient whose kidney failure is a consequence of a primary health condition that is non-reversible, non-treatable, and terminal and for whom dialysis would cause undue suffering. Infants or children who would otherwise be expected to survive for years with conditions causing severe neurologic impairment and who develop ESRD should ordinarily not undergo dialysis or transplant. Examples might be an infant with anencephaly or severe porencephaly, or a child with a severe progressive demyelinating condition. In children with severe developmental disabilities, clinicians will need to discuss with parents the balance of the benefits to burdens of prolonging life with dialysis. An intensification of palliative care treatment should occur in conjunction with any decision to forgo dialysis.

Recommendation No. 7: Consider Forgoing Dialysis in a Patient with a Terminal Illness Whose Long-Term Prognosis Is Poor or if the Patient and the Family Are in Agreement with the Physician That Dialysis Would Not Be of Benefit or the Burdens Would Outweigh the Benefit

In pediatric patients who experience major complications from dialysis that may substantially reduce survival or quality of life, it is appropriate to discuss and/or reassess treatment goals, including considering forgoing dialysis or withdrawing dialysis and initiating or increasing the emphasis on goals commensurate with palliative care. Alternatively, it is reasonable to initiate dialysis for patients with AKI or ESRD who have chronic illness from a non-kidney cause in whom outcome studies have been favorable. For example in human immunodeficiency virus (HIV)-associated nephropathy, dialysis has the potential to improve the quality of life in children.

Recommendation No. 8: Consider the Use of a Time-limited Trial of Dialysis in Neonates, Infants, Children, and Adolescents with AKI or ESRD to Allow for the Assessment of Extent of Recovery from an Underlying Disorder

In an intensive care setting, neonates, infants, children and adolescents with AKI or ESRD as a result of an underlying disorder may be candidates for initiating time-limited trials of dialysis. The purpose of such a trial would be to establish the extent of recovery from the underlying disorder and/or to determine the balance of benefits to burdens that continued life enabled by dialysis provides to the child. The initiation of dialysis in conjunction with extra-corporeal membrane oxygenation (ECMO) is an example of a time limited trial. It is considered time-limited in that the dialysis is most often discontinued when ECMO is withdrawn due to patient non-viability.

Providing Effective Palliative Care

Recommendation No. 9: Develop a Palliative Care Plan for All Pediatric Patients with ESRD from the Time of Diagnosis and for Children with AKI Who Forgo Dialysis. The Development of a Palliative Care Plan Is a Continuation of the Process of Advance Care Planning and Should Be Family-centered

The terminally ill child, family and child's physician(s) should be involved in developing and executing a palliative care plan, based on their

preferences concerning goals of care and decisions regarding testing, monitoring, and treatment. With the patient and family's permission, health care professionals with expertise in hospice and palliative medicine should be involved in co-managing the medical, psychosocial, and spiritual aspects of end-of-life care for the child and family. The nephrology team along with the child's pediatrician and other medical providers should offer bereavement support to the patient's family. In the case of a long-standing relationship with the pediatric patient, nephrology team members are encouraged to send a condolence card to the patient's family. Nephrology team members should be given complete autonomy regarding attendance at a pediatric patient's funeral or memorial service. Nephrologists and the child's health care team are strongly encouraged to seek support, in dealing with the child's dying process and death in the event that the situation causes significant stress that interferes with baseline functioning at work or home.

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

- Acute kidney injury
- Stage 4 or 5 chronic kidney disease
- End-stage renal disease

Guideline Category

Counseling

Evaluation

Management

Risk Assessment

Treatment

Clinical Specialty

Family Practice

Internal Medicine

Nephrology

Pediatrics

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Dietitians

Health Care Providers

Hospitals

Nurses

Patients

Physician Assistants

Physicians

Social Workers

Guideline Objective(s)

- To provide clinicians, patients, and families with: 1) the most current evidence about the benefits and burdens of dialysis for patients with diverse conditions, 2) recommendations for quality in decision-making and treatment of patients with acute kidney injury (AKI), chronic kidney disease (CKD), and end-stage renal disease (ESRD), and 3) practical strategies to help clinicians implement the guideline recommendations
- To provide systematically developed statements to assist practitioner and patient decisions about appropriate healthcare (in this case dialysis) for specific clinical circumstances in neonates, infants, children and adolescents
- To synthesize available research evidence on patients with AKI, CKD, and ESRD as a basis for making recommendations about starting, withholding, continuing, and withdrawing dialysis
- To enhance understanding of the principles and processes useful for and involved in making decisions to withhold or withdraw dialysis
- To promote ethically as well as medically sound decision-making in individual cases
- To recommend tools that can be used to promote shared decision-making in the care of patients with AKI, CKD, or ESRD
- To offer a publicly understandable and acceptable ethical framework for shared decision-making among health care providers, patients, and their families

Target Population

- Infant, neonatal, children, and adolescent patients with acute kidney injury (AKI), chronic kidney disease (CKD), and end-stage renal disease (ESRD)
- Four distinct groups of children who could potentially benefit from dialysis have been identified:
 - Infants with poorly functioning or non-functioning kidneys due to genetic conditions or a urological or kidney abnormality that is non-reversible
 - Infants with AKI without prior evidence of intrinsic kidney disease or urological abnormality
 - Children with AKI with or without prior evidence of kidney problems
 - Children with CKD whose kidney function over time becomes progressively worse

Interventions and Practices Considered

1. Shared decision-making in the appropriate initiation of and withdrawal from dialysis
2. Informed consent or refusal of pediatric patients and their parents
3. Facilitate informed decision
4. Conflict resolution
5. Advance care planning
6. Withholding or withdrawing dialysis
7. Time-limited trial of dialysis
8. Palliative care

Major Outcomes Considered

- Prevalence of withdrawal from dialysis
- Recovery of renal function
- Morbidity

- Mortality
- Quality of life
- Charlson Comorbidity Index score
- Karnofsky Performance Status Scale score
- Complications of dialysis
- Cost

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

Second Edition (2010)

The Renal Physician Association (RPA) sponsored the development of this guideline using essentially the same methodology as the original guideline for adult patients published in 2000. In 2000 there was not sufficient evidence to warrant a pediatric guideline on dialysis decision-making. The RPA revisited the issue more recently, found sufficient new evidence, and the RPA Quality, Safety, and Accountability Committee oversaw this guideline development. Pertinent pediatric English language literature published from January 2003 to October 2009 was identified from the following:

- PubMed
- References from articles
- Experts
- Hand searches of medical and nephrology journals

In addition to the search terms used in the original adult guideline development, palliative care and end-of-life care were also included. Figure 5 in the full version of the current guideline includes a diagram of the article selection process for the guideline revision.

2015

The 2015 systematic literature review was performed by the American Society of Pediatric Nephrology (ASPN) in conjunction with the RPA. For this systematic literature review, the workgroup identified pertinent English language literature published from October 2009 to June 18, 2015. Articles were identified from PubMed, references from articles, experts, and updates to cited guidelines.

In 2015 the search terms used included those in the first and second edition of the clinical practice guideline, and the search was supplemented with the additional following terms: dialysis OR chronic kidney disease AND prognosis, pain, symptoms, advance care planning, shared decision-making, palliative care, end-of-life care, conservative management, initiation, withholding, withdrawal, cost effectiveness, ethics, health economics, or costs and pediatric or pediatrics or child or infant or adolescent or youth. Also searched were combinations of “education,” “shared decision-making,” “dialysis,” “withholding,” “withdrawing,” “modality,” “palliative care,” “supportive care” AND “choice,” “pre-dialysis” AND “withholding,” “dialysis” AND “withdrawal,” “religion,” “culture,” “ethnicity,” “end of life,” “palliative care,” “dialysis” AND “cost-effectiveness,” “palliative” OR “hospice” AND “cost-effectiveness,” “ethics in dialysis,” “shared decision making,” “time limited trial,” “palliative care in nephrology.”

Articles identified using the search terms noted above were included if after the review of the abstract, the article was deemed relevant to the content area of either group.

Number of Source Documents

2010 Guideline

56 studies were included in the evidence base.

2015 Reaffirmation

The literature search identified a total of 339 articles of which 16 articles were identified as meeting inclusion criteria. One of the cited guidelines in the previous guideline had also been updated. These 17 articles (13 in prognosis group, 4 in advance care planning group) were included in the evidence base.

Methods Used to Assess the Quality and Strength of the Evidence

Expert Consensus

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Levels of Evidence for Different Types of Studies

Criteria for grading studies addressing therapy, prevention, and prognosis were adapted from the Centre for Evidence-based Medicine at Oxford's criteria for rating evidence. Criteria for rating observational evidence were developed by the San Antonio Evidence-based Practice Center.

Observational/Descriptive Evidence

- A. Multiple large studies or single nationally representative study with >80% response rate(s).
- B. Multiple small studies from diverse populations with response rates of 60%-80%.
- C. Few studies, selective samples, or low response rates.

Therapy/Prevention

- A. Multiple randomized controlled trials or single trial with narrow confidence interval.
- B. Cohort study or low quality randomized trial (e.g., <80% follow-up, small sample size, unequal co-interventions or biased outcome assessment).
- C. Case-control studies.

Prognosis

- A. Inception cohort studies (multiple or single large representative study) with >80% follow-up, and/or models from such studies validated with test sets.
- B. Retrospective cohort study, prevalent cohort study, or follow-up of untreated control patients in a randomized trial, or multiple studies find similar risk ratios for a given risk factor.
- C. Case-control studies or biased cohort studies with inadequate control for confounding variables, biased outcome, or biased exposure ascertainment.

Methods Used to Analyze the Evidence

Decision Analysis

Review of Published Meta-Analyses

Systematic Review

Description of the Methods Used to Analyze the Evidence

Data Abstraction Process

Standard forms were used to abstract data from each study. Such data included information about study purposes and designs, participant descriptors, methodological characteristics, outcome measures, and results. Items related to the internal validity of studies that were assessed included: selective recruitment of study participants, problematic outcome assessment, high drop-out or nonresponse rates, discordance with current standards of care, confounding cointerventions, inappropriate analysis, and inadequate power.

Seven individuals participated in the abstraction process. To aid standardization of abstraction, teams of abstractors were assigned articles related to specific thematic areas, such as prognosis of acute kidney injury (AKI), prognosis of end-stage renal disease (ESRD), feasibility of dialysis, referral of patients for dialysis, quality of life of dialysis patients, withdrawal of dialysis, preferences, decision-making capacity, and advance directives. Working Group members were assigned to thematic teams based upon their clinical or methodological expertise.

Levels of Evidence

The criteria that were used to rate the quality of evidence are described in Table 3 of the full version of the current guideline. Criteria for grading evidence addressing therapy, prevention, and prognosis were adapted from those of the Centre for Evidence-based Medicine at Oxford (www.cebm.net/index.aspx?o=1025). Criteria for rating observational evidence were developed by the San Antonio Evidence-based Practice Center. The text in the rationales for each recommendation gives the ranking for the body of research evidence relevant to individual statements. When multiple relevant studies of varying quality were available, the evidence was rated according to the highest ranked study.

Methods Used to Formulate the Recommendations

Expert Consensus (Delphi)

Expert Consensus (Nominal Group Technique)

Description of Methods Used to Formulate the Recommendations

2010 Guideline

In developing the original adult guideline, the Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) selected the topic, committed resources towards its development, and organized the creation of a multidisciplinary Working Group to oversee the development process. The RPA and ASN appointed a steering panel that was charged with framing the scope of the guideline, identifying the relevant stakeholders and groups that should be represented on the multidisciplinary Working Group, and outlining the requirements for technical and administrative contractor support to develop the guideline. The panel selected staff from the San Antonio Evidence-Based Practice Center (EPC) and VA Cochrane Center to provide such support using methodology adapted from the Agency for Health Care Policy and Research (AHCPR) guideline process and outlined in the American Medical Association's Attributes for Clinical Practice Guideline Development document. The RPA and ASN announced the guideline process in mid-1998 and invited interested parties to share pertinent ideas and comments with members of the Working Group and the San Antonio EPC/VA Cochrane Center.

The Working Group formulated specific guideline recommendations, taking into account several parameters: 1) ethical principles; 2) legal statutes; 3) shared decision-making; 4) the amount, type, quality, and consistency of supporting research evidence; and 5) the anticipated feasibility of implementation. There was considerable heterogeneity in the types of questions that the Working Group posed and in the types of research studies that were deemed relevant to those questions. Most often, relevant studies were prognostic cohort studies or observational studies (e.g., surveys, case series) that provided descriptive information. In a few instances, randomized controlled trial evidence was considered relevant.

Two analytic frameworks, one for acute kidney injury (AKI) and one for end-stage renal disease (ESRD), were developed to provide a conceptual framework for decisions about withholding or withdrawing dialysis. The models are presented in Figures 3 and 4 in the original guideline document. They depict a dynamic chronological sequence of decision-making that is informed by multiple factors, such as patient preferences, prognosis, and feasibility of dialysis.

The Working Group proposed and prioritized key questions related to the models using a combined nominal and modified Delphi process. Questions specified information that was either desirable or necessary to make informed and ethical decisions about withholding or withdrawing dialysis. Such questions were categorized as directly informative to the evidence model or as background and contextual in nature. These key questions guided analysis of the evidence. The specific evidence questions for decision-making about dialysis in AKI and ESRD are listed in the full version of the current guideline.

The Working Group was provided with background information regarding principles of ethical decision-making. They were also given information regarding guideline development processes and desirable attributes of performance measures that may be used to help insure guideline implementation. They were provided with evidence tables that summarized the available research evidence relevant to the analytic framework questions. Based on these materials, teams within the Working Group formulated draft guideline recommendations. A general consensus process involving the entire group was used to reach agreement on final recommendations.

Formulation of Pediatric Recommendations

The pediatric workgroup was comprised of five pediatric nephrologists, a child psychologist and a pediatric ethicist. The workgroup used the same methodology as the adult workgroups and considered recommendations for pediatric dialysis decision-making for AKI, chronic kidney disease (CKD), and ESRD. In developing their recommendations, the pediatric workgroup reviewed the following: 1) the pediatric recommendations contained in the RPA/ASN 2000 *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* clinical practice guideline; 2) clinical practice guidelines from non-U.S. pediatric nephrology groups; 3) the policy statements, clinical reports, and clinical practice guidelines written by the American Academy of Pediatrics (AAP) and cited on the AAP Web site as of October 2009 and specifically those containing recommended "best practices" regarding the provision of medical care to pediatric patients with AKI, CKD or ESRD; and 4) a draft of the second RPA 2010 adult *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* clinical practice guideline.

2015 Reaffirmation

The Working Group participants affirmed the validity of the present guideline and concluded that there was not a need to revise the guideline at the time.

Rating Scheme for the Strength of the Recommendations

Not applicable

Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

Peer review of the guideline was solicited at multiple points. First, the co-chairs of the workgroup developed the first draft based on the evidence and the format used in the adult guideline. Second, the other members of the workgroup reviewed the draft and provided comments. Third, the recommendations and rationales were formally reviewed by the American Society of Pediatric Nephrology and the American Academy of Pediatrics. This peer review was done to identify any seminal research evidence that was missed in the literature search and any major omissions in recommendations and rationales. The recommendations and rationales were reviewed based on the input from the external reviewers.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The evidence included published research studies and policy statements, clinical reports, and clinical practice guidelines written by the American Academy of Pediatrics.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

This guideline will:

- Assist pediatric nephrologists in communicating their recommendations to medical colleagues and families in an objective and systematic manner (i.e., presenting age and disease-specific research, clinical experience, and information about the patient as the basis for recommending a particular course of action)
- Provide health-care providers who have limited expertise in pediatric kidney disorders with additional information to help them formulate realistic expectations about dialysis interventions
- Provide a decision-making framework for initiating and withdrawing dialysis for neonates, infants, children, and adolescents
- Provide information to primary care providers who are charged with providing a medical home for children with these complex medical problems

Potential Harms

Not stated

Qualifying Statements

Qualifying Statements

- The recommendations are not mandatory, but rather flexible guides that can be tailored to a particular patient, provider, and geographic circumstances. They allow the renal care team to use discretion as they are applied to individual patients. They are intended for use by providers and patients (and their families or advisors) in the United States of America and its trust territories to aid in dialysis decision-making. They are not intended for use by regulatory agencies for reimbursement or other decisions.
- Decisions to either withhold or withdraw dialysis are complex and dependent upon circumstances unique to individual patients and their providers. Although these recommendations are meant to aid in dialysis decision-making, they do not cover every possible contingency. Further, the guideline recommendations do not cover the technical management of patients receiving dialysis nor the selection of patients for renal transplantation, topics which were previously addressed by the Renal Physicians Association (RPA), the National Kidney Foundation, and the American Society of Transplantation.

Implementation of the Guideline

Description of Implementation Strategy

Dissemination and Educational Initiatives

A first step in Guideline implementation is dissemination and education. The Working Group recommends that the Guideline document be disseminated throughout the End-Stage Renal Disease (ESRD) Networks, as well as to individual providers. They also recommended incorporation of the Guideline into nephrology and critical care fellowship training programs and continuing education workshops for practicing renal care professionals. ESRD Networks, professional organizations, and/or providers may use the guidelines to develop patient education materials. Training programs and workshops should provide opportunities for participants to develop and practice skills necessary for implementing the guidelines, such as skills in advance care planning, palliative care, and communication.

Local Implementation

Clinical practice guidelines are successful only to the extent that they improve patient care and outcomes. The limited data available suggest substantial variation among dialysis facilities with regard to advance care planning, completion of advance directives, and provider/patient (family or

legal agent) communication regarding treatment options (including the right to refuse dialysis). One of the fundamental principles of Quality Improvement (QI) is that opportunities for improvement exist whenever there is variability in process and outcomes. Dialysis facilities and their patients could benefit from QI activities that seek to increase communication and shared decision-making between providers and patients or their legal agents regarding treatment and end-of-life decisions.

Quality improvement consists of a cycle of identifying areas in need of improvement, setting achievable goals, targeting activities to achieve these goals, and remeasuring performance. Choosing reliable, specific, valid, reproducible, and interpretable quality indicators will help insure successful implementation and desired improvements in care. Under the 2008 Conditions for Coverage, dialysis facilities are required to have a Quality Assessment and Performance Improvement (QAPI) program.

With these factors in mind, potential quality indicators derived from this Guideline are suggested below to assist local facilities in their QAPI efforts. Depending upon current local practices and available resources, individual facilities are encouraged to consider selecting one or more of the following areas for QAPI activities:

- Increase number of patients with advance care plans in place.
- Increase number of patients who have a designated legal decision-maker in the event of incapacity.
- Decrease number of patients reporting pain.
- Increase number of patients with symptom assessments done.
- Increase number of patients for whom nephrology clinicians have answered the "surprise" question.
- Increase number of terminally ill patients who are referred to hospice.

Suggestions and examples of some tools (e.g., methods for assessing decision-making capacity) that might be used to implement these recommendations are provided in the Toolkit in the full version of the current guideline (see also "Availability of Companion Documents").

Implementation Tools

Audit Criteria/Indicators

Quick Reference Guides/Physician Guides

Tool Kits

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

End of Life Care

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

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Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2010 Oct (reaffirmed 2015 Jun)

Guideline Developer(s)

Renal Physicians Association - Medical Specialty Society

Source(s) of Funding

Renal Physicians Association (RPA)

Guideline Committee

Renal Physicians Association Clinical Practice Guideline Revision Working Group

Composition of Group That Authored the Guideline

2010 Guideline

RPA Quality, Safety, and Accountability Committee Chair: Paul M. Palevsky, MD

RPA Clinical Practice Guideline Revision Working Group Chair: Alvin H. Moss, MD; West Virginia University School of Medicine, Morgantown, WV

RPA Pediatric Clinical Practice Guideline Work Group Co-chairs: Barbara A. Fivush, MD, and Arlene C. Gerson, PhD, Johns Hopkins University School of Medicine, Baltimore, MD

For a complete list of literature review workgroup members and external reviewers, refer to Section 8 of the full version of the current guideline.

2015 Reaffirmation

Participating Members of the American Society of Pediatric Nephrology (ASPN) Sub-committee on Bioethics: Aaron Wightman, MD, MA; Michael Freeman, MD; Jesse Roach, MD; Aaron Friedman, MD; Blanche Chavers, MD

Financial Disclosures/Conflicts of Interest

Not stated

Guideline Endorser(s)

American Academy of Hospice and Palliative Medicine - Professional Association

American Academy of Pediatrics - Medical Specialty Society

American Association of Critical-Care Nurses - Professional Association

American Association of Kidney Patients, Inc. - Disease Specific Society

American College of Nurse Practitioners - Medical Specialty Society

American Geriatrics Society - Medical Specialty Society

American Society of Pediatric Nephrology - Professional Association

Center to Advance Palliative Care - Professional Association

Forum of End-Stage Renal Disease Networks - Nonprofit Organization

Kidney End-of-Life Coalition - Professional Association

National Hospice and Palliative Care Organization - Nonprofit Organization

National Renal Administrators Association - Professional Association

Society of Critical Care Medicine - Professional Association

Guideline Status

This is the current release of the guideline.

The Renal Physicians Association reaffirmed the currency of this guideline in 2015.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Electronic copies: Not available at this time.

Print copies: Available for purchase from the Renal Physicians Association, 1700 Rockville Pike, Suite 220, Rockville, MD 20852; e-mail, rpa@renalmd.org; telephone, (301) 468-3515; fax, (301) 468-3511, or from the [Renal Physicians Association \(RPA\) Web site](#)

Availability of Companion Documents

The following are available:

- Shared decision-making in the appropriate initiation of and withdrawal from dialysis. Recommendation summary. Rockville (MD): Renal Physicians Association (RPA); 2010 Oct. 12 p. Electronic copies: Available in Portable Document Format (PDF) from the [RPA Web site](#)
- Shared decision-making in the appropriate initiation of and withdrawal from dialysis. Toolkit. Rockville (MD): Renal Physicians Association (RPA); 2010 Oct. 37 p. Electronic copies: Available in Portable Document Format (PDF) from the [RPA Web site](#)

In addition, clinical performance measures on end stage renal disease (ESRD) and diabetes are available from the [RPA Web site](#)

Patient Resources

None available

NGC Status

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